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Pain is a universal experience and the most common reason individuals seek medical treatment, accounting to more than 70 million physician visits per year in the United States (Schnall, 2003). It is estimated that pain prevalence is high and that 70 million Americans will experience some for of pain annually (Gatchel & Weisberg, 2000). It is further estimated that 50 million Americans suffer from chronic pain (Marx, 2004). Chronic pain can have a negative impact on the perceived quality of life (QOL) of chronic pain sufferers. Pain locus of control (PLOC) is an appraisal style shown to influence coping in chronic pain patients. The purpose of this descriptive pilot study was to examine differences in PLOC dimensions in chronic pain patients and to assess their perceived QOL. Results of this study show differences in PLOC and QOL as well as difficulty with recruitment.

PAIN LOCUS OF CONTROL AND QUALITY OF LIFE INDEX SCORES IN CHRONIC PAIN PATIENTS: A PILOT STUDY

by

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APPROVAL PAGE

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CHAPTER I

INTRODUCTION

Pain is a universal experience. All individuals experience pain, whether it is psychological, emotional, spiritual, or physical. Pain is the most common reason individuals seek medical treatment, accounting for more than 70 million physician visits per year in the United States (Schnall, 2003). According to Gatchel and Weisberg (2000) the prevalence of pain is extremely high, and is estimated that 70 million Americans annually will experience some form of pain and that 10% of the population will report pain at least 100 days in a year. Despite a plethora of surgical, pharmaceutical, and behavioral approaches to alleviate and manage pain, not all pain can be managed successfully. Researchers have revealed that pain is a complex, multi-faceted biopsychosocial phenomenon uniquely experienced by each individual, and influenced by time, economics, and personality (Schnall, 2003). Pain is necessary as a mechanism for survival and defense against injury. Acute pain functions as a warning system: prompting us to remove a hand from a hot object, avoid overworking pulled muscles, and is common after surgical procedures. Pain may persist long after the original injury has healed and becomes a chronic affliction, rather than a warning system. Chronic pain is defined as pain that is ongoing, lasting six months or longer, unresponsive to conventional treatment, and due to non-life threatening causes (Dysvik, Linstrom, Eikeland, & Natvig, 2004). It is estimated that approximately 50 million Americans

suffer from chronic, persistent pain (Marx, 2004). Chronic pain for some individuals can be quite devastating, preventing them from living normal, healthy lives; others may not experience debilitating effects. Individual appraisal and response to pain are influenced by a number of factors.

Models of stress and coping suggest that perception and cognitive appraisal of stressors are related to preferred coping styles (Seville & Robinson, 2000). One way of conceptualizing pain appraisal is whether a person has an internal or external locus of control (LOC) (Coughlin, Badura, Fleisher, & Guck, 2000; Crisson & Keefe, 1988). Individuals with an internal LOC cope by taking charge; those with an external LOC rely on others. The concept of locus of control developed out of the framework of social learning theory, and simply stated, refers to the perception of control one has over one's health (Toomey, Seville & Mann, 1995). LOC can be broadly categorized as internal or external. An internal LOC reflects belief in personal control over health and health related matters. An external LOC is characterized by belief in actions of powerful others influencing health; or chance, the belief that luck or fate influences health. Researchers have shown that chronic pain patients with an internal LOC report decreased pain frequency and intensity and increased coping strategies (Coughlin et al, 2000). Conversely, chronic pain patients with a LOC relying on chance, fate, or luck (an external LOC) demonstrate maladaptive coping behaviors, greater psychological distress and increase incidence of depression, greater feelings of helplessness, and less ability to control and reduce their pain (Crisson & Keefe, 1988). These general health LOC

concepts of internality and externality have been applied specifically to pain, and referred to as pain locus of control (Toomey, Seville, & Mann, 1995).

Pain locus of control (PLOC) refers to beliefs related to pain control and management, and incorporates the same constructs of internality, and externality (chance, and powerful others) (Toomey, Seville, & Mann, 1995). One PLOC study involving a group of outpatient chronic pain clinic participants demonstrated a higher percentage of chance scores than a similar sample of pain free, outpatient medical clinic patients (Toomey, Mann, Abashian, Carnrike, & Hernandez, 1993). Chronic pain patients with a history of physical or sexual abuse also have been found to have higher chance scores, more emergency room visits, and increased psychological distress than chronic pain patients without a physical or sexual abuse history (Toomey, Seville, Mann, Abashian, & Grant, 1995). Additionally, chronic pain patients with external LOC are more likely to have greater impairment, decreased functioning, and increased incidence of maladaptive coping behaviors than chronic pain patients who have an internal LOC (Coughlin et al, 2000). Considering the prevalence of chronic pain in the United States and the associations some chronic pain patients have with maladaptive coping mechanisms, depression, and psychological distress, one might reflect on their perceived quality of life.

Researchers in Norway found gender differences related to pain intensity and quality of life (QOL) scores as well as treatment for chronic pain (Rustoen, Wahl, Hanestad, Lerdal, Paul, & Miaskowski, 2004). In this particular study men reported a poorer QOL than did women; despite that, more women reported chronic pain as well as

higher pain intensity scores. Another study involving participants of a multidisciplinary pain management program found gender, duration of pain, and intensity as predictors for health-related quality of life (Dysvik, Linstrom et al, 2004). Health-related quality of life refers to a multidimensional, global physical and mental well-being of the individual as measured by eight scales that assess physical and social functioning; physical and emotional roles; bodily pain; general, physical and mental health; and vitality. Clearly chronic pain can have a negative impact on the quality of life for chronic pain sufferers. A research question that has not been explored is the relationship between PLOC and QOL for chronic pain sufferers.

Purpose

The purpose of this pilot study was to assess and describe QOL and PLOC in this sample.

Justification

Conducting this research is important and relevant for several reasons. The first is due to the prevalence of chronic pain. Tens of millions of people seek medical treatment for pain and associated sequelae each year in the United States; the magnitude and prevalence of the condition lends support to the pursuit of a more complete understanding of variables affecting chronic pain management. Second, the information obtained by conducting such research can be used to formulate more effective treatment programs for chronic pain patients, thus potentially resulting in decreased costs and reduced burdens on healthcare delivery systems. PLOC has been shown to be altered in response to in-patient multidisciplinary pain treatment programs (Toomey, Seville, & Mann, 1995) as

well as out-patient chronic pain patients (Coughlin et al, 2000). More effective treatment programs may improve coping, adaptation and self-care skills, and reduce suffering. Knowing an individual's PLOC may also allow healthcare providers treating the patient to customize their teaching and intervention efforts. For individuals with an internal PLOC, practitioners could focus efforts toward self-help skills. For individuals with an external PLOC, the provider could direct the individual to seek help from others for their care needs, potentially including a multidisciplinary treatment approach. A pilot study to assess the feasibility of a larger scale study is necessary to evaluate the practicality of such an endeavor.

Conceptual Framework

Pain locus of control refers to the degree of control individuals believe they have over the pain their experience. PLOC encompasses three dimensions: internality, powerful others, and chance. The subscale categories of powerful others and chance fall under the broad category of external PLOC. An individual has an internal PLOC if they believe their own actions and behaviors have the greatest impact and influence over pain control. An external PLOC that represents powerful others reflects the belief that individuals such as doctors, nurses, family, and religious representatives have the greatest influence. Chance PLOC represents the belief that what happens with pain control is based largely on luck (Toomey, Mann et al, 1993). PLOC is a personality trait that researchers have shown to influence response to chronic pain (Toomey, Seville et al, 1995; Toomey, Mann et al, 1993).

Quality of life can have many meanings. In this study, QOL refers to a comprehensive, multidimensional, self-reported satisfaction with life. QOL domains include health and functioning, psychology, sociology, economics, family, and spirituality. Research supports that chronic pain affects QOL, many times in negative ways by interfering with functional capacities in physical, mental, vocational, family, and social roles (Rustoen et al, 2004; Dysvik, Lindstrom et al, 2004). The relationship between PLOC and QOL will be explored in this study.

Assumptions

1. PLOC can be measured.
2. QOL can be measured.

Research Questions

The research questions investigated in this pilot study are as follows:

- Are there differences in PLOC dimensions (internality, powerful others, chance) in chronic pain patients?
- What is the perceived QOL of chronic pain patients?

Chronic pain was operationally defined as ongoing pain lasting six months or longer. PLOC refers to specific beliefs that an individual holds about pain control; includes the three domains of internality, powerful other, and chance; and was measured using the PLOC Scale (Toomey, Seville et al, 1995; Toomey, Mann et al, 1993). QOL was measured by the Quality of Life Index-Generic Version III (QLI-GVIII) (Ferrans & Powers, 1985).

Definition of Terms

Chronic pain is defined as pain lasting six months or longer, unresponsive to conventional treatment, and due to non-life threatening causes (Dysvik et al, 2004).

Pain Locus of Control refers to the specific beliefs that an individual holds about pain control (Toomey, Seville & Mann, 1995).

Internality is the belief that an individual's behavior influences his or her pain control (Toomey, Seville & Mann, 1995).

Powerful others is the belief that actions of other people influence pain control (Toomey, Seville & Mann, 1995).

Chance is the belief that luck influences pain control (Toomey, Seville & Mann, 1995).

External locus of control refers to the two domains of powerful others and chance (Toomey, Seville & Mann, 1995).

Quality of Life refers to the perceived QOL of the chronic pain sufferer and includes subscales of health and functioning, social-economic, psychological-spiritual, and family (Ferrans & Powers, 1985).

CHAPTER II

REVIEW OF THE LITERATURE

Chronic pain may lead to emotional and psychological dysfunction for some individuals. Others adjust relatively well and do not exhibit pathologic responses to ongoing pain. Social scientists have examined adaptation, coping and response patterns of chronic pain sufferers in an attempt to identify variables associated with these processes. One aspect of personality shown to influence pain response is that of PLOC. A review of the history of the development of the concepts and tools for measuring PLOC is necessary to more completely understand how these concepts have been studied.

According to Wallston, Kaplan, & Maides (1976) in 1966 Rotter developed a scale to measure internal and external LOC. The scale was originally designed as a way to explain individual learning differences and was developed within the framework of Social Learning Theory (Wallston et al, 1976). The original instrument was a unidimensional, forced-choice, self-report test that included 29 items. High scores on the scale indicated a belief that external forces including luck, chance, or actions of others had the greatest influence over the respondent's life and these indicated an external control. Low scores indicated the belief that respondents had control over their own lives, and had an internal attribution of control (Seville & Robinson, 2000). The original Rotter scale was revised by Levenson (1974) to yield three independent subscales

pertaining to beliefs related to control over life situations: internality, powerful others, and chance.

Investigators recognized the potential utility of LOC in chronic disease states, but the original unidimensional design and focus did not allow for application in the healthcare arena. Efforts were made by Wallston and colleagues (1976) to redesign the LOC scale to specifically address health-related beliefs, using the same three independent subscales. The result was the development of the Multidimensional Health Locus of Control (MHLC) scale. High scores on the internal subscale of the MHLC indicate the belief that health is related to individual self-behaviors. Elevated scores in the powerful others subscale indicate that influential others such as healthcare providers and family influence the respondents health. Dominant chance subscale scores indicate chance or fate is most responsible for the state of health of the respondent. Researchers investigating chronic pain patients have used a variety of investigational tools including the MHLC scale or modified versions.

Relationships between LOC, coping strategies and psychological distress in chronic pain patients were examined by Crisson and Keefe (1988). They used a modified MHLC scale, a coping strategy questionnaire, and a revised symptom checklist administered to a group of 62 hospitalized chronic pain patients. These researchers revealed that patients with a chance LOC felt more helpless to deal with their pain and used more diverting attention and praying/hoping strategies. Additionally, these individuals were more likely to catastrophize and avoid their activity to cope with pain. The MHLC scale has also been used in at least one multi-center study.

One study conducted by Kelvinson and Payne (1993) compared patients seeking treatment for chronic pain. One group of 30 was recruited from a complementary treatment center and another group of 30 from two National Health Service pain clinics in England. All participants were administered a MHLC scale and a general health belief model assessment scale. No relationship was found between attendance at a complementary treatment center and general health beliefs. There were, however, significant differences on all three subscales and treatment site locations. Higher internal LOC scores were found in the group receiving care at the complementary treatment center, suggesting these patients "may take more responsibility for their own state of health" (p.4). Pain clinic patients scored higher on both chance and powerful others, indicative of an external LOC. The basic design and format of this MHLC scale was modified and revised to specifically address pain related beliefs.

The MHLC scale was modified by Toomey, Mann, Abashian, and Thompson-Pope (1991) to specifically assess pain related control beliefs and the resultant tool became known as the Pain Locus of Control Scale. The format of the PLOC is nearly identical to the MHLC, consisting of a 36-item questionnaire with a six point Likert format. There are 12 items for each of the three subscales: internality, powerful others, and chance. This scale was used in a study conducted by Toomey, Mann et al, (1993) in which they sought to examine the associations between treatment setting and pain control attributions. The study included 98 outpatients, 48 of whom were seen at a pain clinic and the remaining 50 at a general medical clinic. Twenty-eight of the medical clinic patients were being seen for pain; the remaining 22 were seen for other medical

conditions. Subjects without pain were asked to respond to the PLOC in terms of their usual responses to pain. Pain clinic patients had significantly lower internality and powerful other scores than did the two other groups. The pain clinic patients also had higher chance scores than the medical clinic patients without pain, but lower than medical clinic patients with pain. The authors concluded that attributions of pain control vary across the treatment setting.

The PLOC was used in another study by Toomey, Seville, and Mann (1995) to examine associations of PLOC scores, pain description, self-control skills, and psychological distress. In their study the PLOC scale was administered along with the McGill Pain Questionnaire, an adjectival pain descriptor tool; a Self-Control Schedule to assess the ability to apply self-controlled problem solving methods; and a Global Severity Index that reflects the number of psychological symptoms reported and degree of distress. The subjects of this study consisted of 87 chronic pain patients presenting to an outpatient pain clinic. Data were collected as part of an admission packet prior to the clinic appointment. The results demonstrated that the chance subscale was strongly related to higher pain ratings, decreased self-control coping efficacy, and diminished psychological adjustment. No associations were found between internality, pain ratings, coping, or psychological distress. The authors suggest that the utility of this scale as a clinical predictor may be restricted by a lower ceiling for internality scores for chronic pain patients or medical illness.

With the prevalence of pain in the United States, and the known associated

co-morbidities (i. e., depression, feelings of helplessness/hopelessness, functional impairment, ineffectual coping mechanisms, and elevated distress levels), one might consider the quality of life of chronic pain sufferers. According to Dysvik, Lindstrom et al (2004) chronic pain patients often experience a burden of disease that has a negative effect on health-related quality of life. A study of 81 outpatients of a pain management program in Norway by this group of authors revealed a reduction in all 36 subscales assessed by the Medical Outcomes Survey-Short Form—an instrument frequently used to determine health-related quality of life. Women reported poorer physical health than men; pain duration was positively related to physical health, which was an unexpected finding. The authors suggest that this may indicate a response shift resulting from adaptive psychological mechanisms involved with dealing with chronic pain, that allow previously held beliefs, goals, and expectations to be abandoned and viewed as untenable. Increased pain was inversely related to physical health, while social support had a positive influence on mental health. Variables of pain intensity, inactivity, and decreased tolerance of pain were found to contribute to reduced health.

Another Norwegian study found gender differences for pain and QOL. A mailed questionnaire study of 1912 Norwegian citizens conducted by Rustoen, Wahl, Hanestad, Lerdal, Paul, and Miaskowski (2004) found a higher incidence of chronic pain for women as well as higher pain intensity scores and treatment rates. Men reported a poorer QOL, despite similar chronic pain duration rates. Disease process and pain location were the two variables most strongly associated with gender differences. Osteoarthritis, fibromyalgia, asthma, and osteoporosis were reported more often by women as sources of

chronic pain. A higher percentage of men reported surgery as the cause of pain. Women reported higher instances of pain in the neck and buttock and higher mean number of locations than men. The reasons gender differences exist are unclear. It is postulated that biologic, genetic, hormonal, cardiovascular, social, and psychologic factors may affect the pain experience (Rustoen et al, 2004).

QOL for chronic pain sufferers in the United States, especially as it relates to PLOC, is unclear. Results of Norwegian studies may not be generalized to populations of other countries. What is needed is additional investigation to examine the relationship between these two concepts. Knowledge focusing on the relationship between PLOC and QOL for chronic pain patients in the United States should be studied further.

CHAPTER III

METHODS

Research Design

A descriptive pilot study of PLOC and QOL in a convenience sample of adult chronic pain patients age 21 years and older attending a university affiliated pain clinic was conducted. A pilot study design was selected in order to evaluate the practicality of measuring PLOC and QOL in chronic pain patients; to assess how easily can this be accomplished; and to determine what some of the factors influencing enrollment and participation might be.

Setting

Data were gathered at a North Carolina university affiliated pain clinic. Patients at this clinic typically receive care for the following conditions: spinal, abdominal, joint and neuropathic pain; headaches; fibromyalgia; and complex regional pain syndrome. The age range of these clinic patients was 18 years to 91 years of age. In 2004 the anesthesiologists at the clinic saw 4,964 patients and performed 1,459 procedures.

Population and Sample

A convenience sample of 10 respondents (N=10) from the Raleigh/Durham university affiliated pain clinic was recruited over a nine day period of time. The sample was chosen to test the feasibility of the study as well as for the preliminary examination of relationships between variables before undertaking a larger study. Inclusion criteria

were: (1) adults age 21 years or older; (2) participants were receiving treatment for chronic pain; and, (3) participants were English speaking.

Protection of Human Subjects

Institutional review board (IRB) approval was obtained from Duke University Medical Center and The University of North Carolina Greensboro. Additionally, the PI provided a copy of the certificates of completion of the National Institutes of Health online course, Human Participants Protection Education for Research Teams and Duke specific modules: What Counts as Research with Human Subjects, and Protecting Research Subjects to each of the respective Institutional Review Boards. Written informed consent was provided by all participants.

Instruments

Pain locus of control was measured by the PLOC Scale (Toomey, Mann, Abashian, and Thompson-Pope, 1991). This is a 36-item questionnaire utilizing a 6-point Likert scale numbered 1 to 6. One represents strongly disagree; 2, moderately disagree; 3, disagree; 4, agree; 5, moderately agree; and 6, strongly agree. Each of the three domains: internality; chance; and powerful others consists of 12 items assessing beliefs pertaining to pain. The scale is scored by adding item responses for each of the domains, with the highest domain score representing the dominant PLOC (see Appendix A for PLOC instrument). Written permission to use the scale was obtained from the senior author.

The PLOC scale has been used in a number of studies involving chronic pain patients (Coughlin et al, 2000; Toomey, Mann, Abashian, & Thompson-Pope, 1991;

Toomey, Seville, & Mann, 1995; Toomey, Mann et al, 1993) and has a reported split-half reliability of .89 (Seville & Robinson, 2000).

Quality of life was measured by the Quality of Life Index-Generic Version III (QLI-GVIII) (Ferrans & Powers, 1985). Many versions of this tool have been developed to be used with the general public as well as with individuals who have various disorders. This is a copyrighted tool in the public domain. The reliability, validity, and sensitivity of the instrument have been documented. Internal consistency reliability of the instrument is evidenced by Chronbach's alpha values ranging from .84 to .99 for the total scale, with similar results for each of the subscales (www.uic.edu/orgs/qli). Temporal reliability was supported by test-retest correlations ranging from .78 to .87 for the total scale, as well as correlations of .68 to .79 for overall QOL score in addition to the various sub-scales (www.uic.edu/orgs/qli). Content and construct validity is also supported in the literature (www.uic.edu/orgs/qli). The QLI-GVIII is comprised of 33 items which respondents rate on a 6 point Likert scale from either "very dissatisfied" to "very satisfied", and "very unimportant" to "very important". For the section assessing satisfaction a response of 1 indicates very dissatisfied; 2=moderately dissatisfied; 3=dissatisfied; 4=slightly dissatisfied; 5=moderately satisfied; and 6=very satisfied. For the section assessing importance a response of 1 indicates very unimportant; 2=moderately unimportant; 3=slightly unimportant; 4=slightly important; 5=moderately important; and 6=very important. The index contains four domains including health and functioning, psychological and spiritual, social and economic, and family. Scoring of the instrument results in a score from 0 to 30 for each domain as well as an overall QOL score.

Demographic data were gathered by a Demographic and Health History coversheet (Appendix B) and included interval data for age, categorical data for gender, race/ethnicity, educational background, length of time chronic pain had been present, verification of pain lasting six months or longer, and pain origin. Pain origin also included a space for "other" in the event the check boxes did not include the respondent's pain source. Multiple entries were allowed for race/ethnicity and pain origin. This Demographic Coversheet was developed by the PI in collaboration with the thesis committee members and was not tested for validity or reliability prior to use. Hours spent by the PI and activities associated with enrollment were tracked in a journal.

Data Collection and Field Procedures

Data collection occurred in one university affiliated pain clinic in central North Carolina. The study was designed as a pilot study using a convenience sample of 10 adult chronic pain patients. The PI recruited participants during their appointments to the clinic using a recruitment letter distributed by the clinic reception clerks and nursing staff at the time of check in (see Appendix C). The letter had the signature of the patient's attending anesthesiologist and requested their consideration to participate. It further instructed the patient to hand the letter back to the staff if they wanted to participate or learn more about the study. Once the staff were notified of the patient's interest, the staff notified the PI who then met the patient and took them to a private room to discuss the study and inform them of the details. Written informed consent was obtained of all participants. Participants were provided with a private area to complete the questionnaires and demographic coversheet, and confidentiality was maintained. No

traceable, identifiable information directly connecting the patient to the study was collected. Signed consent forms were kept separate from data forms, code numbers were used on all forms, and a master code list was locked separate from the data forms in the office of the PI. The PI assumed responsibility for possession of all records and their storage.

Data Analysis

PLOC scores were tabulated to determine the dominant domain, i.e., internal, powerful others, or chance for each respondent. This was accomplished by adding the scores for each of the questions used to measure the three domains: internality, powerful others, and chance. QLI-GVIII scores measured overall quality and in the four domains (i.e., health and functioning, social/economic, psychological/spiritual, and family). The SPSS-PC program specifically for scoring this instrument was utilized. Means and ranges for the PLOC and QLI-GVIII were reported. Statistical analysis of data was conducted in conjunction with The University of North Carolina Greensboro School of Nursing Research Office statistician, Dr. Raymond Buck. Assistance from Dr. Buck included consultation in the initial planning phase of study design, demographic sheet development, and determination of sample size, as well as database construction for data analysis and use of the SPSS statistical program. No data were copied to any computer hard disk. Feasibility of the study was determined by calculation of cost associated with hours spent in subject recruitment, calculation of packet completion rate, and review of obstacles for enrollment. Cost of recruitment was calculated by multiplying total hours spent by the PI in the clinic for recruitment by $25 per hour to provide an estimate of

associated expenses. Time spent in the clinic was recorded in a journal. Packet completion rate was determined by dividing the total number of completed packets by the total number of consented participants. Obstacles to enrollment were documented in PI journal entries, reviewed, and reported.

Limitations

The small sample size of this study limits the ability to draw conclusions about adult chronic pain patients in general; results may not be representative of chronic pain patients at large. Additionally, limiting the study to one location and the affiliation of the location to a large university, also limits the ability to generalize results to other groups of chronic pain patients. Limited geographical area served by the location site as well as the limited time in which the study was conducted may also have affected results. Larger sample sizes and multi-centered studies are needed to support or refute the findings.

CHAPTER IV

RESULTS

Demographics

Ten subjects (N=10) participated in the study. A total of fourteen individuals signed consent forms to participate in the study; four participants did not complete the collection tools. Of the ten participants nine were female (90%). The average age of the respondents was 49 years. Three ethnic groups were represented: African American (20%), Asian American (10%), and Caucasian (70%). Sixty percent reported some college experience, 10% less than high school, 20% high school graduate, and 10% beyond college graduate. All respondents reported having pain six months or longer; three (30%) reported having pain four to six years; one (10%) seven to nine years; and the remaining six (60%) for greater than 9 years. The documentation of pain location allowed for multiple entries with 4 (40%) of the respondents documenting multiple sources of pain, five (50%) documenting a single source of chronic pain, and one respondent not indicating their source. Spinal pain was indicated by 5 (50%) of the participants, followed by joint pain, neuropathic pain, complex regional pain syndrome, fibromyalgia, other, and abdominal pain in descending order of prevalence (40%, 30%, 30%, 20%, 20%, & 10% respectively). Ninety percent of the respondents denied being involved in legal litigation and one individual did not answer that question; see Table 1.

Table 1

Demographics & Health History

Variables	
Age: mean	49 years
Standard Deviation	15.2
Gender	
Female	9 (90%)
Male	1 (10%)
Ethnicity	
Caucasian	7 (70%)
African American	2 (20%)
Asian American	1 (10%)
Educational level	
Some college	6 (60%)
High school graduate	2 (20%)
Less than high school	1 (10%)
Beyond college	1 (10%)
Pain present 6 month or longer	10 (100%)
Length of time pain present	
4 - 6 years	3 (30%)
7 - 9 years	1 (10%)
> 9 years	6 (60%)
Pain location (multiple responses accepted)	
Spinal pain	5 (50%)
Joint pain	4 (40%)
Neuropathic pain	3 (30%)
Complex regional pain syndrome	3 (30%)
Fibromyalgia	2 (20%)
Other	2 (20%)
Abdominal pain	1 (10%)
Not specified	1 (10%)
Single source of pain	5 (50%)
Multiple sources of pain	4 (40%)
Legal litigation	
Not specified	1 (10%)
No	9 (90%)

Of the ten respondents only one completed every item on each of the data collection tools (PLOC, QLI-GVIII, and demographic coversheet). Eighty percent of the respondents omitted items on the QLI-GVIII. Of those omissions 60% were related to item number 21 assessing the importance and satisfaction with their job, if employed. Four individuals wrote in comments including: NA, none, and not. One additional respondent omitted a similar item, item number 22. This particular item assesses satisfaction and importance of not having a job if unemployed, retired, or disabled. Other items not answered on the QIL-GVIII included satisfaction and importance of their faith in God; sex life; spouse, lover, partner; doing things for fun; family health; and children. Twenty percent of the participants omitted answers to questions for item number 9 which assesses satisfaction and importance of children. Both respondents wrote in comments indicating they did not have children. Forty percent of respondents omitted answers to more than one item.

Ninety percent of the respondents completed the PLOC in its' entirety. One participant omitted answers to items 3, 6, and 34; one question came from each of the three subscales. For the purposes of data analysis a response of 3 was entered for these items for data analysis. This same individual circled responses 3 and 4 for two items, number 8 and 23; the results were calculated using a value of 3.

Pain Locus of Control

Overall, 50% of subjects scored highest in the subscale domain of powerful others, followed by internal 40%, and chance 10%. The minimum and maximum possible scores for each of the subscales are 12 and 72. Of the ten subjects, one failed to answer

three items on the PLOC tool. Analysis of subscales for this subject on these non-response items was completed by first entering a non-extreme answer of three on the six-point Likert scale, followed by re-analysis with entries of one, and then six on each of the respective items; these manipulations did not change the dominant domain. Mean subscale score results for all participants were as follows: powerful others 43.7, chance 33.8, and internal 32.8. Examination of the range of subscale scores revealed the greatest variability in the domain of chance, and least in the domain of powerful others. See Table 2 for greater detail.

Table 2
Pain Locus of Control Results

Subscale Information	
Internal	
Subscale dominance	4 (40%)
Score range	18 - 47
Mean subscale score	32.8
Standard deviation	10.7
Powerful others	
Subscale dominance	5 (50%)
Score range	35 - 53
Mean subscale score	43.7
Standard deviation	6.7
Chance	
Subscale dominance	1 (10%)
Score range	17 - 55
Mean subscale score	33.8
Standard deviation	9.7

Quality of Life Index Scoring

The range of overall QLI-GVIII scores was 4.64 to 25.86; the range possible is 0 and 30. The QLI-GVIII tool also provides information in four subscale domains: health and functioning, social-economic, psychological-spiritual, and family. Analysis of the subscales for all respondents irrespective of their PLOC domain revealed the greatest variance in the psychological-spiritual subscale, with the range of scores equaling 0 to 30. Health and functioning was the subscale with the second greatest variability in scoring, followed by family, and social-economic. Several of the subjects did not circle responses to some of the questions as described in earlier paragraphs. The questions with the greatest non-response rate were those related to employment and children. A number of the participants indicated on the data collection forms they were not employed or did not have children. For all questions that were blank a response of 3 on the 1 to 6 Likert scale was entered rather than treating nine of the ten packets as missing data. Analyzing the omitted entry as a score of 3 out of 6 impacted the mean scores.

The QLI-GVIII scores were also grouped by PLOC subscale domains of internal, chance, and powerful others. One respondent was determined to possess the dominant domain of chance PLOC. When this individual's QLI-GVIII scores were calculated it was revealed that the overall score was 6.74, the second lowest of all QLI-GVIII scores. The lowest QLI-GVIII score was found in the PLOC powerful others domain. When comparing the internal and powerful others domains, the greatest range of QLI-GVIII scores was found in the powerful others group (4.64 - 25.86). In addition, the PLOC

powerful others group displayed lower scores for each of the QLI-GVIII subscales when compared to the internal group. Specific details can be found in Table 3.

Table 3
Quality of Life Scores: Includes Overall QLI-GVIII results and by PLOC Subscale Categories

Overall range N=10	4.64 - 25.86
Subscale scores N=10	
Health & functioning subscale range	0.58 - 25.85
Social-economic subscale range	10.19 - 27.94
Psychological-spiritual subscale range	0.00 - 30.00
Family subscale range	2.40 - 30.00
Internal PLOC N=4	
Health & functioning subscale score range	11.58 - 21.04
Social-economic subscale score range	19.44 - 22.13
Psychological-spiritual subscale score range	13.21 - 24.64
Family subscale score range	14.70 - 30.00
Powerful others PLOC N=5	
Health & functioning subscale score range	0.58 - 25.85
Social-economic subscale score range	10.19 - 27.94
Psychological-spiritual subscale score range	0.00 - 30.00
Family subscale score range	2.40 - 28.80
Chance PLOC N=1	
Health & functioning subscale score	4.19
Social-economic subscale score	13.13
Psychological-spiritual subscale score	5.57
Family subscale score	6.00

Cost Analysis and Practicality

Data were collected over a period of nine days for eight hours each day, for a total of seventy-two hours. This resulted in one packet with every item of all data collection tools completed. All others were missing information. This is a completion rate of 7.1% (one completed packet of fourteen enrolled). An idea of the dollar amount required just to solicit and enroll participants can be estimated by multiplying the 72 hours spent in the clinic by the PI by $25 per hour, for a cost of $1,800. This does not include time spent by clinic staff in solicitation, the time required of the PI for preparation of materials, or time required for data analysis. Analysis of these additional components would involve elements not included in the current study, but, if factored in, would drive the associated costs higher than the current estimate.

Review of journal entries demonstrated two main reasons for lack of enrollment: lack of patient time to complete the documents and lack of expressed interest. Other reasons for failure to enroll included a failed communication by clinic staff to the PI of one patient's expressed interest in learning more about the study; one patient that did not meet the inclusion criteria of pain lasting six months or longer; and one patient lacking the cognitive ability to give consent. In this study enrollment was difficult and costly, and obtaining complete data packets was practically impossible.

CHAPTER V

DISCUSSION

Summary of Major Findings

Although this was a very small pilot study in one chronic pain clinic and cannot be generalized, there are aspects to be considered. Recruitment of chronic pain patients for this study was a challenge; enrollment averaged one per day. There are many possible explanations for this phenomenon. For example excessive pain or side effects of medications such as sleepiness or fatigue may prevent adequate concentration to complete multi-page questionnaires. Participation in research activities might have been perceived as a waste of time or useless. Additionally, the number of hours needed to complete enrollment and obtain data were excessive as well as non-productive. Of the ten packets returned only one was completed in its' entirety.

As this was a pilot study, determining statistical significance with a sample size of 10 was not possible. It is interesting to note however that even with such a small sample there was variability in the types of PLOC domains detected, with a combined sixty percent scoring dominant for powerful others and chance. Review of the results in Table 3 demonstrates higher starting values for overall QLI-GVIII scores and for each subscale domain for individuals with an internal PLOC.

Limitations

The small number of participants (N=10) is a major limitation of the study resulting in inability to generalize findings to other populations. Additionally, methodological limitations are present and include difficulty in recruitment of subjects for the study. Enrolling participants proved to be difficult and expensive. Clinic staff responsible for initiating contact with potential subjects reported concerns related to the amount of time required to complete the data collection tools and lack of patient interest in participation. The expense of the study became a factor when considering the hours the PI spent at the clinic waiting for subjects to agree to participate. Nine days were spent by the PI at the clinic to acquire packets for ten participants, only one of which was completed in its' entirety. Manhours needed for subject enrollment became a factor hindering recruitment of additional participants.

Additional limitations were related to the data collection tools. Each tool consisted of multiple pages and although answering the questions involved the simple process of circling a response, there remained the time and effort necessary to read, consider, and respond to each of the items. This may have seemed daunting to some, particularly if they did not feel well, had difficulty reading, or were experiencing side effects from medications or treatments. Additionally, some of the questions proved difficult for some subjects to answer, particularly those associated with employment and children. Finally, the location of the study may have also impacted results.

The study was conducted at a large teaching hospital associated chronic pain clinic. It is unknown if the types of patients receiving care at this clinic are similar to or

different from those attending other chronic pain clinics. Also, it is not known if patients seen at chronic pain clinics are a fair representation of persons suffering from chronic pain but receiving care by other means such as family practitioners or self-treatment. Further research would be required to answer these questions.

Implications for Future Research

Implications for future research include the need to identify effective data collection tools that will provide valid and reliable information for pain locus of control and QOL for chronic pain patients. These tools would need to have demonstrated validity and reliability across a variety of pain populations, genders, cultures, and ethnicities. Additionally, shorter tools that require less time and effort to complete may promote participation in studies, and reduce the time required and costs associated with such projects. The manner in which these tools are administered also needs to be considered. It may prove helpful to have someone read the items to the subjects, or perhaps allow them to take the tools home to complete and return at a future time. Future research can help answer these questions pertaining to data collection tools and methods across pain populations as well as providing guidance for further theory development.

Implications for Theory

Evidence suggests multiple factors such as demographic and individual differences influence responses to chronic pain. Seville and Robinson (2000) reported that stress and coping models have been used to examine the adaptation and adjustment processes of chronic pain patients. Specifically, strategies of cognitive appraisal, that is

perceptions of stressors, are linked to preferred coping styles (Seville & Robinson, 2000). PLOC has been identified as one component of the complex appraisal process that occurs in chronic pain patients. Cognitive appraisal of stressors may also impact perception of QOL, however, there is insufficient evidence in the literature to support or refute this conclusion. Additionally, it is unknown how an individual's PLOC and QOL might evolve and change over time or what factors might influence changes. Further research into potential relationships between external or internal PLOC and QOL would be needed to advance our theoretical base. This research would need to be conducted using standardized assessment tools that have demonstrated validity and reliability across a variety of pain populations, genders, cultures, and ethnicities. Developing a more comprehensive understanding of chronic pain patients will likely inform clinicians how to best reduce their physical and emotional suffering, develop effective multi-disciplinary treatment programs, and decrease acute care admissions.

Implications for Clinical Practice

There are several implications for practice that can evolve out of this study. Firstly, it is important for clinicians working with chronic pain patients to realize that these patients may feel overwhelmed, have trouble concentrating, and not want to be bothered with what are perceived as unnecessary tasks. These feelings may not only impact how they perceive their QOL but their ability and willingness to participate in activities such as research. Difficulty with enrollment of these patients in research projects ultimately drives up the costs associated with the research, may skew results, and

leave the healthcare community with inaccurate evidence upon which to build effective treatment systems.

Secondly, it is important to acknowledge that not all chronic pain patients are alike. Both internal and external PLOC can be found in this population, and approaches to constructing a patient-centered, collaborative plan of care may need to be individualized based on their PLOC orientation. For example, individuals with an internal PLOC may prefer to have greater involvement in the creation, implementation, and evaluation of the plan of care. External PLOC patients may prefer less involvement and decision making and more directives from the healthcare provider. Knowledge of the dominant PLOC subscale can help guide clinicians in their approaches to pain management.

Finally, meeting the needs of this patient population can be a challenge. Co-morbid conditions such as anxiety, depression, and maladaptive coping strategies may prove difficult to treat and result in frustration for healthcare providers. Use of a PLOC assessment tool and the information obtained from its' analysis may aid providers in establishment of a more effective treatment plan thereby reducing acute care admissions and associated costs, and enhancing the QOL of this patient population.

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APPENDIX A

Pain Locus of Control Data Collection Tool

	Instructions: This is a measure of your personal beliefs, there are no right or wrong answers. Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each item is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item please circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please answer **EVERY ITEM** and circle **ONLY ONE** number per item.	Strongly Disagree	Moderately Disagree	Disagre	Agree	Moderately Agree	Strongly
1	If my pain gets worse, it is my own behavior which determines how soon I will get relief.	1	2	3	4	5	6
2	No matter what I do, if my pain is going to get worse, it will get worse.	1	2	3	4	5	6
3	Having regular contact with my physician is the best way for me to avoid my pain getting worse.	1	2	3	4	5	6
4	Most things that affect my relief of pain happen to me by accident.	1	2	3	4	5	6
5	Whenever my pain gets worse, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am in control of relieving my pain.	1	2	3	4	5	6
7	My family has a lot to do with my pain getting worse or better.	1	2	3	4	5	6
8	When my pain gets worse I am to blame.	1	2	3	4	5	6
9	Luck plays a big part in determining how soon my pain is relieved.	1	2	3	4	5	6
10	Health professionals control relief of pain.	1	2	3	4	5	6
11	When my pain is relieved, it is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing that affects relief of my pain is what I myself do.	1	2	3	4	5	6
13	If I take care of myself, I can relieve my pain.	1	2	3	4	5	6
14	When my pain is relieved, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15	No matter what I do, my pain is likely to get worse.	1	2	3	4	5	6
16	If it's meant to be, I will have relief from pain.	1	2	3	4	5	6

	Instructions: This is a measure of your personal beliefs, there are no right or wrong answers. Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each item is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item please circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please answer **EVERY ITEM** and circle **ONLY ONE** number per item..	Strongly Disagree	Moderately Disagree	Disagree	Agree	Moderately Agree	Strongly Agree
17	If I take the right actions, I can relieve my pain.	1	2	3	4	5	6
18	Regarding relief of my pain, I can only do what my doctor tells me to do.	1	2	3	4	5	6
19	If my pain gets worse, I have the power to relieve it.	1	2	3	4	5	6
20	Often I feel that no matter what I do, if pain is going to get worse, it will get worse.	1	2	3	4	5	6
21	If I see an excellent doctor regularly, my pain is likely to get worse.	1	2	3	4	5	6
22	It seems that relief from pain is greatly influenced by accidental happenings.	1	2	3	4	5	6
23	I can only relieve my pain by consulting health professionals.	1	2	3	4	5	6
24	I am directly responsible for relief of my pain.	1	2	3	4	5	6
25	Other people play a big part in whether my pain gets better or worse.	1	2	3	4	5	6
26	Whatever makes my pain worse is my own fault.	1	2	3	4	5	6
27	When my pain gets worse, I just have to let nature run its course.	1	2	3	4	5	6
28	Health professionals relieve my pain.	1	2	3	4	5	6
29	When I have relief from pain, I'm just plain lucky.	1	2	3	4	5	6
30	My relief from pain depends on how well I take care of myself.	1	2	3	4	5	6
31	When my pain gets worse, I know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
32	The type of care I receive from other people is what is responsible for how much my pain is relieved.	1	2	3	4	5	6
33	Even when I take care of myself, it's easy for my pain to get worse.	1	2	3	4	5	6
34	When my pain gets worse, it's a matter of fate.	1	2	3	4	5	6
35	I can pretty much relieve my pain by taking good care of myself.	1	2	3	4	5	6
36	Following doctor's orders to the letter is the best way for me to relieve pain.	1	2	3	4	5	6

Modified by T. C. Toomey, J. D. Mann, S. Abashian, & S. Thompson-Pope (1993). Printed by permission of surviving senior author, J. D. Mann.

APPENDIX B

Demographics and Health History

Thank you for participating in this study. Please take a few moments and tell us about yourself.

Date of Birth:_____ **Gender** ☐Male
(Month/Day/Year) (Please Check) ☐Female

Race/ethnicity (Please check all that apply)
☐ African American ☐ White ☐ Hispanic
☐ Asian American ☐ Native American ☐ Mixed
☐ Other_____

Educational Background (Please check the box next to the highest grade completed)
☐ Less than High School ☐ High School Graduate
☐ Some College ☐ College Graduate
☐ Beyond

Have you experienced chronic pain (pain lasting 6 months or longer)?
(Please Check)
☐ Yes ☐ No

Length of time chronic pain has been present (Please check)
☐ 6 months, but less than 1 year
☐ 1 – 3 years
☐ 4-6 years
☐ 7-9 years
☐ longer than 9 years

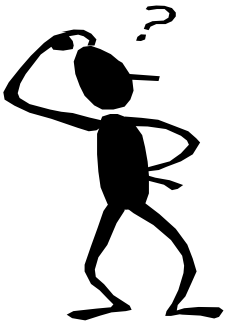
Pain Origin (Please check all that apply. You may ask the nurse or doctor if you are unsure of your medical diagnosis. This is available in your medical record)

___ Spinal Pain ___ Abdominal Pain ___ Joint Pain
___ Neuropathic Pain ___ Complex Regional Pain Syndrome
___ Fibromyalgia
___ Other--please list_____

Are you currently involved in any type of legal litigation? (Please check)
☐ Yes ☐ No

APPENDIX C

Recruitment Letter



Dear Patient:

Sherry Keck, RN, is doing a study on pain and quality of life. Mrs. Keck is a graduate student in the nursing program at The University of North Carolina at Greensboro. We support the study and would like you to think about taking part. The decision to take part or not is totally up to you. If you do not want to take part it will not change your care. There is no cost to you. The study asks you to answer a few questions about pain, your quality of life, your age, how long you have had pain, and a few other things. It will take about thirty minutes to do and can be done while you are here. If you want to take part or want to learn more, just give this letter back to our clerk and Mrs. Keck will take you to a room where she will explain more.

Sincerely,